

Statement of Testimony

Disabled Services in the District of Columbia: Who is Protecting the Rights of D.C.'s Most Vulnerable Residents?

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Thank you, Mr. Chairman. My name is Bob Gettings. I am the Executive Director of the National Association of State Directors of Developmental Disabilities Services. In that capacity, I am responsible for assisting developmental disabilities agencies in the fifty states and the District of Columbia to expand and improve publicly funded long-term supports for individuals with mental retardation and other lifelong disabilities. The mission of NASDDDS is to assist member state agencies to develop effective and efficient service delivery systems that furnish high-quality services to persons with developmental disabilities.

I also serve in a voluntary capacity as a member of the Board of Directors of the Quality Trust for Individuals with Disabilities, an independent, nonprofit organization created as part of the 2001 Compliance Plan in the *Evans* class action lawsuit. The mission of the Quality Trust is to advance the individual and collective interests of residents of the District of Columbia with developmental disabilities as well as their family members and friends.

I do not appear before you today as an official representative of NASDDDS, or as a spokesperson for the Quality Trust. Instead, I've been asked to share with you my personal observations concerning the principal characteristics of an effectively managed service delivery system for persons with developmental disabilities. These observations are drawn from over 40 years of experience in working with state and local officials to improve services to this population.

The Changing Management Environment.

When I began my career in the early 1960s, the limited public services then available to children and adults with mental retardation were furnished almost exclusively in large, severely overcrowded state institutions, many of which were located in isolated rural communities. Services – such as they were – were furnished by state employees, under the direct supervision on-site managers. With the exception of a few, scattered day care centers operated mainly by local parent organizations, there were virtually no community services provided outside of public school special education classes, which in many communities refused to serve youngsters with severe disabilities.

The situation has changed dramatically over the intervening decades. The number of individuals residing in state-run institutions plummeted from over 200,000 in the early 1970s to 42,514 in 2004.¹ Meanwhile, the number of persons receiving specialized community DD services has climbed to over 750,000. Eighty percent of the \$38.55 billion the states expended, collectively, on specialized DD services in 2004 financed community services,² most of which were managed by private sector agencies.³

¹ Bruninks, Robert, et. al., *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2004*, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota/Minneapolis, July 2005, page 8.

² Braddock, David, *State of the States in Developmental Disabilities: 2005*, American Association on Mental Retardation: Washington, D.C., 2005, page 8.

³ Bruninks, et al. report that, as of June 30, 2004, of the 420,202 persons receiving residential services, 87.1 percent were been served in non-state operated settings; and, if you focus on persons living in settings for one to six

I point these changes out simply to underscore the fact that the task of managing public developmental disabilities service systems is much different today than it was 20 or 30 years ago. The skills it takes to directly administer a public facility, staffed by state workers, are not the same as the skills required to negotiate and oversee the performance of a widely dispersed network of contractual services furnished through private vendor agencies. In the present environment, government must assume responsible for steering, rather than rowing, the ship of state, to draw upon the image popularized by Osborne and Gaebler in the early 1990s.⁴ States that have successfully navigated the transition to a privately managed DD service system have hired public managers with the necessary skills to ensure that vendor agencies are qualified to perform their assigned functions and then systematically monitored and held accountable for their performance. Drawing upon the experiences of these states, let me share with the Committee my observations concerning the critical issues that need to be addressed in order to improve the management of developmental disabilities services in the District of Columbia.

Fixing Accountability and Responsibility for District DD Services.

Two of the foundational rules of public administration are that: (a) authority must be commensurate with responsibility; and (b) public servants must be held accountable for their performance. At present, neither of these rules is consistently followed in the management of the city's services to individuals with developmental disabilities. Under the District code, the Department of Human Services, acting through the Mental Retardation and Developmental Disabilities Administration (MRDDA), is responsible for assuring that services are provided to eligible individuals and that such services are furnished in an effective and efficient manner. But, because the city, like all 50 states, relies heavily on federal-state Medicaid dollars to finance specialized DD services, the bulk of service funding is channeled through the budget of the Medical Assistance Administration (MAA) in the D.C. Department of Health, which functions as the District's single state Medicaid agency (SSMA). As a consequence, funding and managerial authority for the city's DD services are divided between the budgets of two departments, making it difficult to develop and carry out a unified approach to serving individuals with developmental disabilities.

Federal regulations (42 CFR 431.10) assign to the single state Medicaid agency (SSMA) responsibility for ensuring that all Title XIX-funded services comply with applicable federal regulations. But, federal rules also permit the SSMA to enter into interagency agreements with other agencies of state government, as long as it retains authority to: "... (i) [e]xercise administrative discretion in the administration or supervision of the [state Medicaid] plan;" and to "... (ii) [i]ssue policies, rules and regulations on program matters."⁵ Over the years, most states have consolidated day-to-day responsibility for managing Medicaid-funded and non-

individuals (the most rapidly growing out-of-home living settings), 98.1 percent live in non state settings. Ibid, page 63.

⁴ Osborne, David and Ted Gaebler, *Reinventing Government: How the Entrepreneurial Spirit is Transforming the Public Sector*, Penguin Books, USA: New York, NY, 1993.

⁵ 42 CFR 431.10(e)(1).

Medicaid-funded services to individuals with developmental disabilities within the state MR/DD agency. Consistent with federal Medicaid policies, these arrangements are carried out in accordance with an interagency agreement between the SSMA and the state MR/DD authority that spell out the methods to be used to ensure that the single state Medicaid agency retains effective oversight of all applicable Title XIX-funded services. The Centers for Medicare and Medicaid Services (CMS), the agency responsible for administering the Medicaid program at the federal level, has repeatedly approved such interagency agreements, recognizing "... that it may be more efficient and effective for a state" to manage services in this manner.⁶ A 2002 survey commissioned by CMS, in fact, found that day-to-day management of Medicaid-funded home and community-based waiver services to persons with developmental disabilities was assigned to the state MR/DD agency in two-thirds of the states.⁷

In the District of Columbia, prompt steps need to be taken to develop an effective interagency agreement between MAA/DoH and MRDDA/DHS governing the management of Medicaid dollars that support services for persons with developmental disabilities. This agreement should **mandate the development and management of a unified budget for specialized DD services** within the District government. This unified budget should encompass all sources of Medicaid and non-Medicaid funding, including both city matching dollars and anticipated federal payments for ICF/DD, targeted case management, and home and community-based waiver services. Consistent with the dictates of federal Medicaid policy regarding the rule-making and state plan oversight responsibilities of MAA/DoH, **the central aim of this interagency agreement should be to assign clear, unambiguous authority to MRDDA to manage all specialized developmental disabilities services offered by the city in a unified manner, regardless of the source of revenue.** As the experiences of many other states have demonstrated, the consolidation of program and fiscal authority is an essential prerequisite to effectively managing services to this population.

At the present time, MRDDA has nominal authority to manage the city's DD waiver program under an interagency agreement between MRDDA and MAA. But, in practice, control of the waiver budget as well as the development and issuance of waiver management policies still rests with MAA, and past efforts to modify those policies have resulted in excruciatingly long and often fruitless interagency negotiations. For example, staff from MRDDA and MAA's Office of Aging and Disability began meeting over a year ago, with the stated aim of modifying several key features of the city's DD waiver program that prevent the financing of more flexible and responsive services for eligible individuals. Yet, despite the development of detailed recommendations by a specially constituted task force, the two agencies appear to be no closer today to resolving their differences and modifying the existing waiver rules than they were when the negotiations began.

⁶ See Appendix A, *Instructions, Technical Guide and Review Criteria, Application for a Section 1915(c) Home and Community-Based Waiver* (Version 3.3), November 2005, pages 63-66.

Modernizing the City's Approach to Financing and Delivering Services.

As Forest Haven, the city's only institution for persons with mental retardation was downsized and eventually closed in 1990, District officials decided to open a network of privately run group homes to accommodate former facility residents. The city's aim at the time was to provide former Forest Haven residents with a more home-like living environment, while at the same time off-setting federal Medicaid revenues that otherwise would have been lost by certifying these group homes as intermediate care facilities for persons with mental retardation (ICFs/MR). Unlike most jurisdictions, however, the District continues to rely on the ICF/MR service model as its primary method of drawing down federal revenue to support DD services. In FY 2004, the District Government spent \$187.5 million on specialized services for persons with developmental disabilities. HCB waiver expenditures totaled \$11.9 million, or about 3 percent of the city's total DD spending. The balance was spent on reimbursements to ICF/DD facilities (59.5% of the total, or \$111.5 million), day habilitation services (13.2%, or \$24.8 million) targeted case management services (\$20.3 million, or 10.8%) and unmatched city general revenue expenditure (\$26.3 million, or 14%).⁸

Over the past fifteen years, most states have adopted the Section 1915(c) waiver authority as their primary vehicle to claim federal Medicaid reimbursement for DD community services. As of June 30, 2004, more than four times as many individuals were receiving HCB waiver services (424,855) as were residing in public and privately operated ICF/MR facilities. Only ten years, earlier more individuals were being served in ICF/MR facilities (142,118) than were enrolled in HCB waiver services (122,075). As of June 30, 2004, only about one out of ten individuals (11.6%) who were living in small community residences (serving 1 to 15 individuals) were residing in an ICF/MR-certified facility.⁹ In sharp contrast to this pattern, the overwhelming majority of individuals who were receiving Medicaid-funded out-of-home residential services at the time were living in community-based ICF/MR facilities.

Among the primary reasons most states have elected to finance services through the Medicaid HCBS waiver authority is that it:

- ü Affords them far greater latitude in tailoring support strategies to the individual needs and preferences of each participant and his or her family, thus allowing consumers to choose from a wider range of support options;
- ü Represents a generally more economical approach to organizing and delivering services since states are not obligated to provide 24-hour, wrap-around supports to all recipients, as they are under the ICF/MR model.¹⁰

⁸ Braddock, Ibid, pages 102-3.

⁹ Lakin, Ibid, pp. viii-ix.

¹⁰ The average per capita cost of ICF/MR services in the U.S. in 2004 was \$114,132; whereas, the average per capita costs of HCB waiver service ran \$36,497. The contrast was even sharper in the District of Columbia, with the average per capita cost of ICF/MR services running \$108,105 in 2004, compared to an average per participant cost for HCB waivers services of \$14,796 per annum [Lakin, Ibid, pp. 96 and 103].

- Ü Allows states to qualify a much wider range of services and supports for federal reimbursement since residence in a particular type of living environment (an ICF/MR-certified facility serving four or more unrelated individuals) is not a prerequisite for the receipt of federal Medicaid payments;
- Ü It makes benefits far more portable so that a recipient's place of residence and support plan can be more easily altered as his/her needs and preference change; and
- Ü Permits states to offer self- and family-directed support options, an approach strongly favored by a growing number of waiver participants and their families.

In order to develop a programmatically and fiscally sustainable program for serving city residents with mental retardation and other developmental disabilities, **District officials must move aggressively to create a Medicaid home and community-based MR/DD waiver program that functions effectively.** In 1998, D.C. became the last jurisdiction in the nation to receive CMS approval to operate a home and community-based waiver program for this general target population; and, it still operates one of the smallest MR/DD waiver programs, relative to the overall size of a state's DD budget, in the country. The plaintiffs in the *Evans* lawsuit, with the strong backing of the federal court, have been pressing city officials to restructure and expand HCB waiver services for the past several years, with limited success.

There are no secrets to fashioning an effective HCBS waiver program; indeed, there are abundant examples of effective operational designs available simply by drawing upon the experiences of other states. Advice from outside experts may expedite the process of re-designing the District's existing waiver program. But, as I emphasized earlier, **unless existing lines of responsibility and accountability are clarified and a single District official is assigned the authority necessary to ensure that the task is successfully and expeditiously completed, recent history strongly suggests that the waiver renewal process will remain mired in a sea of bureaucratic infighting.** In the past, the District Government has commissioned several analyses of the city's MR/DD waiver program and received thoughtful recommendations on how it might be restructuring to improve participation level and expand access to needed benefits. Yet, none of those recommendations have been implemented thus far and the reports continue to gather dust on government bookshelves.

A well-designed waiver program alone, however, will not necessarily trigger substantial reforms in service delivery practice. Lacking a clear strategy for reallocating expenditures between major spending categories as they presently exist, the growth in waiver services will be dependent on the availability of new city matching dollars (which are in short support at the moment) to draw down additional federal payments for services covered under a revamped waiver program. **What's needed is a global plan or blueprint for restructuring the financing and delivery of ALL specialized DD services along more flexible, consumer-centered lines, of which the steps necessary to redesign the waiver program becomes an integral but subordinate part of the overall strategy.** Planning changes in the waiver program in isolation from a strategy for offering ICF/DD residents, CRF residents and center-based day habilitation participants expanded opportunities to live independent, productive lives in the community will only perpetuate the fragmented planning and policy development that has long plagued the city's DD

service system. Other states, for example, have developed bridge funding strategies to assist community provider agencies to transition persons from ICF/MR facilities to move personalized and integrated community living arrangement of their choice. The District of Columbia should consider employing a similar strategy. Similar steps can and should be taken to shift participants from segregated day habilitation centers and sheltered workshops to integrated support employment programs financed through the HCBS waiver program.

Creating an Effective Quality Oversight and Improvement System.

The 2001 Compliance Plan in the *Evans* lawsuit calls for MRDDA to develop a comprehensive quality management program to ensure that all members of the class are safe, healthy and receive the habilitation and support services specified in their individual service plans. Yet, primary responsibility for monitoring compliance with city rules currently rests with the Health Regulation Administration (HRA), located in the D.C. Department of Health. HRA is responsible for licensing all residential and daytime settings where DD services are furnished as well as for certifying all providers of Medicaid-funded services, including services furnished in ICF/DD-certified group homes, Community Residential Facilities and day service programs that participate in the city's DD waiver programs. Because of this division of responsibility and the absence of effective interagency cooperation between MRDDA and HRA, private provider agencies often receive mixed signal from the two agencies on where the emphasis should be placed in developing and delivering services to persons with developmental disabilities. Provider agencies have long complained that HRA's licensing requirements and reviews focus primarily on the maintenance of the physical plant, largely ignoring in the process the quality and appropriateness of the habilitation services being furnished to facility residents and day program participants. Meanwhile, as dramatically documented in evidence presented to the federal district court over recent years, the limited quality oversight programs initiated by MRDDA (especially its incident reporting and mortality review programs) often have proven to be ineffective in shielding recipients of city services from harm. Nor, have District officials been able to articulate a clear strategy for assuring that existing monitoring and oversight activities are carry out in a coordinated manner that adheres to a common set of goals, objectives and operating practices.

As with service financing arrangements, **there is an urgent need for the District Government to develop a global plan for monitoring and improving the quality of services and supports to city residents with developmental disabilities.** Within the next seven months, the city will have to submit to CMS a request to renew its DD waiver program, which is scheduled to expire in the fall of 2007. Within the past two weeks, the city has retained an outside consulting firm to assist MAA and MRDDA officials in preparing a waiver renewal request; but, as I suggested earlier, there are numerous, long-standing issues that will need to be resolved before the District Government can prepare and submit a request that is likely to be approved by CMS. One of the issues that must be confronted is the design and implementation of a comprehensive quality management program.

Over the past two years, CMS has substantially revamped the process it expects states to use in preparing and submitting Section 1915(c) waiver applications. These changes are incorporated in a new waiver application template that was released in the fall of 2005. The centerpiece of CMS' new waiver application is a requirement that states describe and be prepared to carry out a

comprehensive quality management program.¹¹ A state's quality management program must address a minimum array of design elements that are set forth in CMS' Quality Framework and, of at least equal importance, a state must be able to demonstrate that it has the capacity to not only identify sub-standard conditions and sub-par services but also to institute targeted improvement strategies at both an individual and systems level to rectify such problems once they are uncovered. Given the District Government's dismal record of addressing even the most egregious, life-threatening deficiencies in the quality of care, the preparation and implementation of a credible quality management plan represents a major challenge. This task, therefore, should be assigned very high priority if the District Government expects to receive approval of its DD waiver renewal request.

Fixing the Existing Case Management System.

Case managers or service coordinators, as they often called, act as an essential linchpin in any well-designed, effectively managed community service system for people with developmental disabilities. Positioned on the frontlines of the service delivery system, case managers serve as the eyes and ears of the system: safeguarding the interests of persons on their caseload and advocating on their behalf for more and better services; coordinating the development of individual, person-centered service plans; helping individuals and families to access needed specialized and generic services; negotiating needed modifications in services and supports with responsible providers; and identifying emerging problems before they blossom into major concerns.

Largely as a result of court intervention, MRDDA has one of the most favorable case manager-to-client caseload ratios in the nation, especially for members of the *Evans* class. Yet, the performance of the city's case management system has been poor for many years, according to all available reports. The Court Monitor in the *Evans* case, for example, has repeatedly documented the system's failure to meet even the most fundamental expectations spelled out in the 2001 Evans Compliance Plan. It seems clear that, if city services for people with developmental disabilities are to improve, **assertive steps will need to be taken to substantially upgrade the performance of MRDDA's case management staff.** To achieve such improvements, it will be necessary to: (a) appoint a strong, knowledgeable leader to head up MRDDA's case management operations; (b) establish more and better training opportunities for case managers; (c) strengthen the supervision of District case managers; (d) institute a performance monitoring system for case managers that is modeled after the approaches that some states have had in place for years; and (d) hold individual case managers directly accountable for their performance.

If after careful analysis city officials conclude that it is not possible to institute the recommended changes in policy and practice within the structure of the District's personnel system, consideration should be given to out-sourcing the provision of case manager services to a private contract agency. Should the District decide to privatize case management services, however, it will be essential to retained within MRDDA the capacity to monitor the performance of the case

¹¹ See Appendix H (Quality Management Strategy) in *Application for a Section 1915(c) Home and Community Waiver*, Centers for Medicare and Medicaid Services, October 2005 and Appendix G of *Instructions, Technical Guide and Review Criteria*, Centers for Medicare and Medicaid Services, November 2005.

management agency and enforce the provisions of the vendor contract. In addition, providers of other direct DD services should be ineligible to bid on the case management contract in order to avoid potential conflicts of interest.

Concluding Thoughts.

Faced with the catastrophic consequences of the city's past failure to protect its most vulnerable citizens from harm, there is an understandable tendency to grasp for quick solutions. Certainly, anyone familiar with the current problems facing the District's DD service system must acknowledge the need for prompt corrective actions. Immediate steps to stabilize the situation, however, need to be linked to a broader set of systemic change strategies aimed at improving the city's capacity to effectively manage services for individuals with developmental disabilities over the long haul.

One central lesson that can be drawn from the sad history of the *Evans* litigation – and, indeed, from other, similar class action lawsuits across the country – is that deep-seated systemic failures won't be resolved by a series of quick, overnight fixes. The service system needs to be re-built from the bottom up, and that requires committed and sustained leadership from government officials at all levels – especially top level elected and appointed officials.

I have attempted to offer the Committee some insights into a few of the fundamental flaws in the District's existing MR/DD service system that lie behind the city's continued inability to protect the welfare of vulnerable citizens with lifelong disabilities. I've also tried to pinpoint several critical issues that need to be addressed as part of any attempt to improve District services to citizens with developmental disabilities.

I want to thank you Mr. Chairman for this opportunity to share with the Committee my views on this vitally important topic. I will be happy to respond to any questions the Committee may wish to raise or amplify any of the points covered in my testimony.